# Canadian Journal of Bioethics Revue canadienne de bioéthique



# In Our Own Words: A Qualitative Exploration of Complex Patient-Provider Interactions in an LGBTQ Population

Saba Malik, Zubin Master, Wendy Parker, Barry DeCoster and Lisa Campo-Engelstein

### Volume 2, Number 2, 2019

URI: https://id.erudit.org/iderudit/1062305ar DOI: https://doi.org/10.7202/1062305ar

See table of contents

### Publisher(s)

Programmes de bioéthique, École de santé publique de l'Université de Montréal

ISSN

2561-4665 (digital)

Explore this journal

#### Cite this article

Malik, S., Master, Z., Parker, W., DeCoster, B. & Campo-Engelstein, L. (2019). In Our Own Words: A Qualitative Exploration of Complex Patient-Provider Interactions in an LGBTQ Population. *Canadian Journal of Bioethics / Revue canadienne de bioéthique*, 2(2), 83–93. https://doi.org/10.7202/1062305ar

#### Article abstract

While sexual and gender minorities are at increased risk for poor health outcomes, there is limited data regarding patient-provider interactions. In this study, we explored the perspectives of LGBTQ patients and their encounters with physicians in order to improve our understanding of patient-physician experiences. Using purposive selection of self-identified LGBTQ patients, we performed fourteen in-depth semi-structured interviews on topics of sexual orientation and gender identity, as well as their perceived role in the patient-provider relationship. Coding using a modified grounded theory approach was performed to generate themes. We identified three major themes that demonstrate the complexity of LGBTQ patient experiences. The first, Lacking trust, identifies mistrust and loss of the physician-patient relationship resulting from physicians' poor or judgmental communication, or from physicians making assumptions about gender, using incorrect pronouns, and not recognizing heterogeneity within the transgender community. A second theme, Being vulnerable, describes the challenges and fears related to comfort of patients with disclosing their sexual orientation and/or gender identity. A final theme, Navigating discrimination, outlines racial or ethnic discrimination which creates an additional burden on top of illness and stigmatized identity. Our results reveal the complex needs of individuals with multiple stigmatized identities when developing relationships with providers. By using an intersectional perspective that appreciates the plurality of patients' identities, providers can help to improve their relationships with LGBTQ patients. Incorporating intersectional training for medical students and residents could greatly benefit both LGBTQ patients and their physicians.

All Rights Reserved © Saba Malik, Zubin Master, Wendy Parker, Barry DeCoster, Lisa Campo-Engelstein, 2019



érudit

This document is protected by copyright law. Use of the services of Érudit (including reproduction) is subject to its terms and conditions, which can be viewed online.

https://apropos.erudit.org/en/users/policy-on-use/

### This article is disseminated and preserved by Érudit.

Érudit is a non-profit inter-university consortium of the Université de Montréal, Université Laval, and the Université du Québec à Montréal. Its mission is to promote and disseminate research.

https://www.erudit.org/en/

**ARTICLE** (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

# In Our Own Words: A Qualitative Exploration of Complex Patient-**Provider Interactions in an LGBTQ Population**

Saba Malik<sup>1</sup>, Zubin Master<sup>2</sup>, Wendy M. Parker<sup>3</sup>, Barry DeCoster<sup>4</sup>, Lisa Campo-Engelstein<sup>5</sup>

#### Résumé

Bien que les minorités sexuelles et de genre courent un risque accru de problèmes de santé, on dispose de peu de données sur les interactions patient-prestataire de soins. Dans cette étude, nous avons exploré les perspectives des patients LGBTQ et leurs rencontres avec les médecins afin d'améliorer notre compréhension des expériences patient-médecin. À l'aide d'une sélection ciblée de patients LGBTQ auto-identifiés, nous avons réalisé quatorze entrevues semi-structurées en profondeur sur des sujets comme l'orientation sexuelle et l'identité de genre, ainsi que leur rôle perçu dans la relation patient-fournisseur. Un codage utilisant une approche modifiée de la théorie ancrée a été effectuée pour générer des thèmes. Nous avons identifié trois grands thèmes qui démontrent la complexité des expériences vécues par les patients LGBTQ. La première, le manque de confiance, identifie la méfiance et la perte de la relation médecin-patient résultant d'une mauvaise communication des médecins ou d'un jugement porté sur eux, ou du fait que les médecins font des suppositions sur le genre, utilisent des pronoms incorrects et ne reconnaissent pas l'hétérogénéité dans la communauté transgenre. Un deuxième thème, être vulnérable, décrit les défis et les craintes liés au réconfort des patients face à la divulgation de leur orientation sexuelle ou de leur identité de genre. Un dernier thème, la discrimination sélective, met en relief la discrimination raciale ou ethnique qui crée un fardeau supplémentaire relationships with providers. By using an intersectional perspective en plus de la maladie et de l'identité stigmatisée. Nos résultats révèlent les besoins complexes des personnes aux multiples identités stigmatisées lorsqu'il s'agit d'établir des relations avec les prestataires. En utilisant une perspective intersectionnelle qui tient compte de la pluralité des identités des patients, les prestataires peuvent aider à améliorer leurs relations avec les patients LGBTQ. L'intégration d'une formation intersectionnelle pour les étudiants en médecine et les résidents pourrait grandement profiter aux patients LGBTQ et à leurs médecins.

### Abstract

While sexual and gender minorities are at increased risk for poor health outcomes, there is limited data regarding patient-provider interactions. In this study, we explored the perspectives of LGBTQ patients and their encounters with physicians in order to improve our understanding of patient-physician experiences. Using purposive selection of self-identified LGBTQ patients, we performed fourteen indepth semi-structured interviews on topics of sexual orientation and gender identity, as well as their perceived role in the patient-provider relationship. Coding using a modified grounded theory approach was performed to generate themes. We identified three major themes that demonstrate the complexity of LGBTQ patient experiences. The first, Lacking trust, identifies mistrust and loss of the physician-patient relationship resulting from physicians' poor or judgmental communication, or from physicians making assumptions about gender, using incorrect pronouns, and not recognizing heterogeneity within the transgender community. A second theme, Being vulnerable, describes the challenges and fears related to comfort of patients with disclosing their sexual orientation and/or gender identity. A final theme, Navigating discrimination, outlines racial or ethnic discrimination which creates an additional burden on top of illness and stigmatized identity. Our results reveal the complex needs of individuals with multiple stigmatized identities when developing that appreciates the plurality of patients' identities, providers can help to improve their relationships with LGBTQ patients. Incorporating intersectional training for medical students and residents could greatly benefit both LGBTQ patients and their physicians.

#### Keywords

LGBTQ, santé, relation patient-médecin, intersectionnelle, inégalités LGBTQ, health, patient-physician relationship, intersectionality, health disparities

### Mots-clés

de santé

### Introduction

Understanding the issues related to LGBTQ health is an important and growing area of research and scholarship within bioethics [1-3]. Sexual and gender minorities are at increased risk for various adverse health outcomes [4-11]. Sexual minorities face social stigma and discrimination over their lifetimes, frequently causing significant stress, increased chronic health problems, and maladaptive coping behaviours [4-8]. Research on sexual and gender minorities and health has gained traction over the past few decades, yet limited data exists with regards to patients and their interactions with health care providers.

Lesbian, gay bisexual, transgender and queer (LGBTQ) self-identified patients may experience health disparities or discrimination from health providers that can harm the patient-provider relationship and affect negatively the health outcomes of patients. Questions surrounding how LGBTQ patients select physicians and maintain relationships with health providers remain largely unexplored. For example, what qualities in a physician are considered when choosing a provider, and how is trust in a patient-physician relationship maintained or lost? Several studies have shown that sexual and gender minorities are at increased risk of a variety of adverse health outcomes [4-11]. Sexual and gender minorities are at higher risk for violent hate crimes, sexually transmitted infections (STIs) including HIV/AIDS, mental health conditions, substance abuse, and other adverse health outcomes [4-5]. Social stigma, prejudice, and discrimination towards sexual minorities over the life course can cause significant stress and result in chronic health problems or can perpetuate the use of maladaptive coping behaviours [4-7].

It is clear from the current literature that there have been few, yet promising, efforts to use narrative methodology to determine quality of patient-physician relationships or comfort of sexual and gender minorities in a healthcare setting [12-17]. Investigating the quality of patient-physician relationships is crucial to improving the health of this population. For example, sexual orientation of the patient, if openly self-identified, can become a hindrance to patient-physician communication especially if the patient senses hesitancy on the part of the physician after disclosure [18]. This can get in the way of trust and respect between the two parties which is incredibly important for fostering an effective medical relationship in order to address specific health needs. LGBTQ patients' trust in the medical establishment may have already been compromised due to a history of medical legitimization of invasive procedures in homosexual males and refusal of treatment for transgender individuals [19]. Issues of trust are often exasperated by intersections of minority status, such as is the case for ethnic and racial minority LGBTQ individuals [10]. Research has shown that improving patient-physician relationships allows for increased shared decision making, improved patient satisfaction, and better patient health outcomes [5,20-23]. Approaching patients with an understanding of intersectionality and inquiring about that individual's priorities may improve the development of these relationships.

Intersectionality is a theoretical concept described as the interlacing of multiple identities such as gender, sexual orientation, race and ethnicity, socioeconomic status, education level, among others, and how each component of a person's identity is inseparable from the other [24]. Each aspect of identity is interdependent on the others in formulating an overall experience. This allows a more complicated understanding of how forces of discrimination and oppression (racial, gender, sexuality), which should be understood as a complex set of forces, rather than the simple addition of these forces. Such intersecting forces can both overlap yet still negatively affect people in different ways. Intersectionality has been used across multiple disciplines to describe the intersection of multiple identities with social issues and structural barriers, including those that contribute to health disparities [25-26]. This framework is often used as a lens through which to view individual experiences in relation to social issues, power dynamics, and health disparities as well as the unique needs of minority populations. Intersectionality requires physicians to take a comprehensive look at all spheres of influence on an individual's health and quality of life. Its importance has been highlighted by the American Association of Medical Colleges (AAMC) as its application in medicine can provide guidance, help remediate structural barriers for underserved populations and so reduce the reliance on simplistic interpretations of identity and culture [27]. While the concept of intersectionality and its application in physician practice is evolving, we believe such an approach can and will improve patient care.

The purpose of this study was to explore LGBTQ patients' experiences and relationships with their providers in order to gain a better understanding of existing disparities in care and identify areas where improvements can be made to patient-physician relationships for this population. We report on three major themes: *lacking trust, being vulnerable,* and *navigating discrimination.* Our results illustrate the complex needs of individuals with multiple stigmatized identities when developing relationships with providers. By understanding multi-faceted and complex identities through an intersectional perspective, providers can improve their relationships with their LGBTQ patients. Incorporating intersectional training for medical students and residents could greatly benefit LGBTQ patients and their physicians.

## Methods

### Terminology

Like other specific public groups, the LGBTQ community is not homogenous. "Trans" will refer to individuals whose assigned gender at birth differs from the gender with which they identify. For example, a male to female transgender individual is a transwoman, whereas a female to male is a trans-man. The transgender community may also include individuals who are gender-fluid or gender non-conforming and who do not identify with the traditional male/female binary. For individuals whose assigned gender at birth is consistent with the gender with which they identify, the term we will use is "cisgender" or "cis". Other terms used in this paper refer to variances in sexual orientation and include Lesbian, Gay, Bisexual, Queer (a more broad and reclaimed term for some individuals identifying as other than heterosexual that can sometimes include individuals who identify their sexual orientation. All interviewee descriptors and labels are self-reported by the participant on how they chose to describe themselves.

### **Recruitment and Participant Demographics**

In order to explore the depth of LGBTQ patient perceptions, we adopted a qualitative approach using individual interviews. A convenience sample of LGBTQ participants living in New York state was recruited from two LGBTQ centres after obtaining permission from both organizations. Centre 1 is a community organization providing resources for HIV positive individuals and Centre 2 is a regional community centre serving the needs of the LGBTQ community. We have omitted further recruitment information in order to protect participant privacy. Prior to conducting interviews, participants were given an information sheet about study procedures and written informed consent was obtained. Participants were given a \$20 grocery store or Walmart gift card for participation. Ethics review was conducted and approved by Albany Medical Center Committee on Research Involving Human Subjects Institutional Review Board prior to participant recruitment.

Fourteen individual interviews were conducted over a two-month period at the Centre 1 (10 participants) and Centre 2 (4 participants). Participants (by chance fell within the age range of 28-57) consisted of 3 cisgender women, 8 cisgender men, and 3 transgender women. In terms of sexual orientation, 6 identified as gay, 4 as bisexual, 2 as heterosexual, 1 as queer, and 1 preferred no label. Participants were from a diversity of racial/ethnic backgrounds including 6 who identified as Caucasian, 5 as African-American, 2 as Hispanic, and 1 as both African-American and Peruvian.

### **Interviews and Qualitative Analysis**

Semi-structured interviews consisted of a series of questions around self-rated health, access to the health care system, sexual orientation/gender self-identification, demographics, and the patient-provider relationship from patients' perspectives. Interview questions were developed based on existing literature [29-34] and pre-tested with three experts who study ethical issues surrounding sexual and gender minorities to ensure question clarity and appropriateness. The interview guide was modified accordingly (see Supplemental Materials: Interview Guide). Individual interviews (30-60 minutes) were conducted in English. Interviews were recorded using a digital voice recorder, transcribed by a third-party provider, and transcripts were validated against audio recordings and de-identified of any personal information. Participants were recruited and interviewed until data saturation, specifically until similar themes arose from the interviews conducted.

Analysis of interview transcripts was performed by the primary coder (SM) using an abridged grounded theory approach [35] with constant comparison analysis [36] with a codebook that was inductively developed. The primary coder first performed a descriptive analysis of all of the transcripts followed by a second round of coding to develop overarching themes. Qualitative coding was performed using QSR International NVivo version 10 to develop themes.

# Results

The analysis of the interviews resulted in three major themes that demonstrate the complexity of experiences among this specific group of sexual and gender minority individuals.

### Lacking Trust: Communication, Mis-gendering, and Respect

One theme that emerged centred on the importance of trust in the patient-provider relationship and how it can be damaged through poor communication, mis-gendering, and disrespect. Clinicians' use of medical jargon and explanatory tone significantly affects whether patients will continue to see the provider [37]. Poor communication by physicians can lead to mistrust and ultimately the loss of the physician-patient relationship [37]. For LGBTQ patients, and patients in general, poor communication often hinders establishing a mutually respectful relationship. Some interviewees expressed a need for providers to communicate respectfully and intelligibly, as one participant explained:

I have [gone] to doctors who've talked down to me using just only doctor language and I have to say what is that, what is that? There's an incident where a doctor would tell me what I have or what they found but didn't explain to me what that was, so I walked. (Participant 13, heterosexual transwoman)

Another participant reported a negative experience due to a provider's condescending tone:

I hate when people depreciate me. I'm no longer in [kindergarten]...My parents taught me [you have] got to give respect to get respect. You know, so if you're not going to respect me or...just want to shovel me in and shovel me out, it doesn't work like that. (Participant 7, gay cisman)

Many providers are unfamiliar with the needs of transgender patients [38]. Yet, participants wanted physicians' acceptance:

There are not many people that treat transgender patients. One of the biggest [problems] that a lot of people in the transgender community [have] is finding a care provider that will be open [and] accepting instead of judging. Even for endocrinologists there are not many out there that do that. (Participant 12, bisexual transwoman)

For participants, trusting providers requires open and nonjudgmental communication and mutual respect.

Many transgender participants cited *mis-gendering* – making assumptions about gender without clarifying patients' identity or verifying a patient's previous documentation – as disrespectful. Not all transgender patients equally prioritized its importance, given personal preferences or transition status. Most transgender patients, however, appreciated being asked preferences and only began to feel disrespected when repeated, willful mistakes failed to reflect patients' wishes.

Walking into the doctor's office, it would always be, 'miss, miss, miss...' and they would ask me, 'Are you pregnant? Did you do a Pap smear?' And I'm like, 'did you look at my own records.' (Participant 13, heterosexual transwoman)

The participant then goes on to describe a more respectful and appropriate approach to transgender or gender-variant patients:

'What's your pronoun? How would you like to be addressed?' Or if you're looking at someone's file and you see it says 'Ted' but then you look up and Ted looks like Tammy. You might want to just say, 'How do you identify?' And I find that if a physician uses words like 'What is your pronoun?' 'How do you identify?', [it] gives us [a] sense of comfort. Wow! They're at least on the same page. (Participant 13, heterosexual transwoman)

For many transgender or gender-variant individuals, much of the physician-patient relationship hinges on a mutual respect that often is expressed in the physician's understanding of gender identity and the patient's preferred pronouns; yet basic knowledge about pronouns may not be enough. As this interviewee discusses, providers need to recognize that there is heterogeneity among sexual and gender minorities:

Being transgender doesn't mean one thing and that's the thing that shocked [me] the most is I thought everybody was like me. ...Well, I'm currently [a] girl, but there's some transgender [people who] are boys, [or] are more butch, some are right in the middle, some like guys, some like girls, some like both. So then you get into the middle... where you have gender neutral or it doesn't matter. (Participant 14, heterosexual transwoman)

For transgender and gender variant individuals, it is especially important that their providers recognize how they identify and individualize their care appropriately.

### Being Vulnerable: Disclosing Sexual Orientation or Gender Identity

Another theme addressed the vulnerability of disclosing personal information. Many interviewees described concerns they had about disclosing their sexual orientation and/or gender identity to their health care professional. These concerns contributed to their comfort with discussing personal issues with their providers. The following participant described how a provider might approach the topic:

Not just assuming one thing or anything, just asking very open, honest questions...So like instead of saying 'do you sleep with men and do you sleep with women', 'are you sexually active [and] with whom?' (Participant 11, queer ciswoman)

The importance of disclosure to their providers was stressed by many interviewees:

Of course if you don't tell them, they won't know [anything] about you. (Participant 8, bisexual cisman)

I feel that [anyone] that's taking care of me physically...they should know [if] you're homosexual, bisexual, straight. (Participant 7, gay cisman)

Yet, interviewees were often hesitant to disclose their sexual orientation because they were concerned about the provider's response. Interviewees were sensitive to providers' change in demeanor after disclosure, as it suggested a discomfort with the patient.

When I did disclose it, I felt as if something changed in him. (Participant 4, gay cisman)

But some people like Dr. [de-identified], I think once I told him I was gay that kind of turned him more, you know, he was kind of standoffish with me. (Participant 7, gay cisman)

Such reactions may cause the patient to stop disclosing personal information and hinder the patient-provider relationship [18]. At least one participant claimed that disclosing gender identity was more challenging than disclosing sexual orientation.

At least gay, lesbian, [and] bisexual people are well-known and more accepted than transgender people...The difficult part [is] explaining to a doctor that, 'Hey I am also transgender'...to this day there [are] still people that don't understand transgender people. (Participant 12, bisexual transwoman)

Most interviewees described some challenges related to disclosing their sexual orientation and/or gender identity. This burden of disclosure may often be in the setting of multiple minority stressors, such as racial/ethnic structural discrimination, economic disadvantages, or other stigmatized identities. However, most participants still felt it was important for providers to know their orientation and/or gender identity and for providers to improve their approach to asking about it. For many individuals, disclosing something as personal as orientation or gender identity required being vulnerable to the reaction of the other person, in this case the provider.

### Navigating Discrimination: Burden of HIV and Racial/Ethnic Discrimination

A third theme focused on discrimination that participants faced not related to sexual orientation or gender identity. Since participants were recruited from a community organization focused on providing care for HIV positive individuals, many interviews revolved around HIV stigma and management. One individual described the process of discovering his HIV status and how the provider responded inappropriately to his vulnerability:

I think it was the very first time I had to really face the fact that I was HIV positive and what it meant and all the things that could happen to me. So I was in a very bad space emotionally and so I kind of broke down. And his response was kind of like 'man up'. Like you know, get a hold of yourself. And it just – it totally was

the most [disturbing] thing that a doctor could have done to me. And it turned me off... for a little while I didn't trust doctors... of course that was the last time I saw him but I internalized what he said and I took it around with me for a little while. (Participant 4, gay cisman)

Another individual described an experience of feeling stigmatized by his own physician because the physician seemed afraid to touch him:

They are scared to get close to you. I said, well how did you get [to] the position of being [an] HIV doctor when you're scared to touch the patient. All you want to do is give us this medication...and then call the next morning and let you know how it worked. No, it doesn't work like that with me. (Participant 8, bisexual cisman)

The physician's reluctance to touch the patient revealed an overall reluctance to care for the patient – a message that was clearly felt by the patient.

For at least one participant, the stigma of HIV was much greater than the stigma of their sexual orientation:

People like me who are older, we can say without any hesitation who we are and what we want because we started identifying ourselves as HIV positive long before we started identifying ourselves or maybe at the same time, our gayness and our HIV-ness. Having HIV was like having the scourge of the earth, you know what I mean. So much worse than being gay and if I can identify myself [as] having AIDS, then my god, being gay is nothing compared to having HIV. (Participant 5, bisexual ciswoman)

Additionally, many patients experienced stigmatization regarding their HIV status, thereby compounding the burden of stigmatized gender/sexuality minority identities. It may thus be necessary to broaden the original definition of intersectionality to include HIV status and other clinically relevant stigmatized identities. Participants thought providers should respond appropriately to patient vulnerability and emotions.

Racial/ethnic identities also influenced patient experiences. For example, one African American participant described how her treatment by physicians had been influenced by both assumptions regarding her race as well as her chronic illness. She referenced stereotypes about drug-seeking behaviour in racial/ethnic minorities in the context of her inadequate pain management:

The things that they say about you being a drug addict, you just want pain medicine, you just want whatever, oh just pull yourself [up] by [your] bootstraps. [They are] perpetuating today's negative stereotypes. (Participant 11, queer ciswoman)

This participant went on to describe other racialized assumptions:

First of all they see you, they see I'm a brown women and they're like, "Oh, another one. Well what's your education?" I'm like, "You don't know, I could be a doctor too." And then if I seem like I'm invested in my health, they pick it up as black woman power (like trying to be dominant) [but] if it was a white woman doing the same thing...they would say, "oh she's being in charge." (Participant 11, queer ciswoman)

For some participants, racial/ethnic background was a source of discrimination and stereotypes, an additional stressor on top of illness and stigmatized identity.

## Discussion

Our results show that many within the LGBTQ community worry about disclosing their sexual orientation and/or gender identity to their provider despite feeling that it was important for their provider to know. We argue that this dilemma is shaped by patients' rational responses to systems of oppression in medicine (both real and perceived), rather than a moral failure of patients. Many fear that disclosure would lead to discomfort or judgment on behalf of the provider [3,19,39-40]. Yet, failure to disclose can have adverse health outcomes, such as delaying medical diagnoses and hindering shared decision-making and patient autonomy [39-40]. Furthermore, non-disclosure of orientation or gender identity due to fear of judgment may result in fewer opportunities for preventive care [39]. In contrast, one study found that higher levels of sexual orientation disclosure are associated with greater health service use among sexual minority cis-gendered men [39]. Another study looking at cancer patients also found a positive association between sexual orientation disclosure to care providers and self-rated health [40].

The fear surrounding disclosure is closely related to the theme of respect and communication. Many participants in our study were concerned due to previous negative experiences, especially regarding poor communication and judgmental attitudes, making them reluctant to disclose potentially stigmatizing information. Some of these negative experiences can be considered micro-aggressions; common examples experienced by the LGBTQ community include assumptions of heteronormativity, the lack of inclusive intake forms that offer options for same-sex relationships or options to identify as trans or non-binary, in addition to encounters that invalidate the role of the patient's life partner in decision-making or ignoring the life partner

altogether [3]. Patients sensing hesitancy from their providers after disclosure ultimately can limit patient-physician communication [40].

The narratives also reflect the broader literature that there are differences in health needs and concerns among different segments of the LGBTQ population and that this is not a homogenous patient population [18]. Many of the issues that participants expressed having with providers were less around sexual orientation for cisgender individuals and more around issues of provider practices in terms of trust, empathy, comfort, and discrimination related to race, HIV status, or other chronic health conditions. Gender identity was more of a central issue among the transgender patients in terms of developing trusting relationships with providers.

Many patients experience challenges based on multiple aspects of their identity, suggesting that an *intersectional* approach to physician education and training may improve patient-physician relationships among diverse populations. Intersectionality recognizes the importance of understanding patients' overall experiences via the interlacing of their multiple identities (e.g., gender, sexual orientation, race, socioeconomic status) [24-26]. Intersectionality prioritizes individual experiences in relation to social issues, power dynamics, and health disparities as well as the unique needs of minority populations. Intersectionality requires a comprehensive view of all spheres of influence on an individual's health and quality of life.

Participants in our study identified serostatus as a meaningful axis in need of intersectional attention. For many, their HIV status added additional identity meanings and raised further discriminatory fears or burdens, including discriminatory assumptions made about the patient's activities that caused their infections. More attention should be given and research done on serostatus as an axis of intersectional health analysis.

For marginalized and minority populations, patients' multiple burdens may cause overwhelming long-term stress, negatively affecting their well-being and quality of life. Facing discrimination or microaggressions from health providers, LGBTQ patients may be less likely to trust medical professionals, weakening the physician-patient relationship. One participant who identified as Hispanic, gay, and HIV+, stated that "physicians should have... an idea [of] all of the facets [of] the person...people are so multidimensional" (Participant 4, gay cisman). Physician-patient relationships based on mutual respect and an understanding of patients' complex identities and needs are more likely to result in shared decision making and patient adherence. An intersectional and individualized approach to patient care would enable physicians to positively influence historically marginalized and disadvantaged communities [41].

Intersectional approaches to patient care might also improve a physician's ability to develop relationships with LGBTQ patients by addressing the impact of systems of discrimination and oppression on patients' lives. Providers can improve their relationships with patients by becoming aware of how the power gap between patients and providers is influenced by existing power dynamics and bias [26]. As Baker and Beagan described in *Making Assumptions, Making Space: An Anthropological Critique of Cultural Competency and its Relevance to Queer Patients*, "cultural competency" training has historically valued physician neutrality in order to avoid being insensitive or uncertain, but this instead reinforces a heteronormative and cisnormative narrative when interacting with a largely invisible LGBTQ population [18]. Neutrality discourages providers from asking their patients questions about their identities and cultures for fear of making assumptions. Yet, these questions and conversations are necessary for disclosure for many patients and serve as a foundation for "safe spaces," or places to be vulnerable without judgment; these conversations can serve as an acknowledgment of an individual's complex lived experience [18]. If a patient knows that a provider or clinic is a safe space, they are more likely to be vulnerable and disclose personal aspects of their identity.

In addition, an intersectional analysis allows patients to have richer ways to understand themselves and their own identities. This can improve self-analysis, but also doctor-patient interactions. First, an intersectional analysis provides a theoretical framework for patients to better identify the source of personal values that are shaping their healthcare decisions. In addition, as we have argued, it allows for an understanding that when values conflict, this is a product of an intersectional analysis, rather than an irrational or unthoughtful patient. Second, it allows patients a means by which they can understand personal complexities as real and as a resource, rather than a political statement that should be overcome or ignored when engaging physicians.

Similarly, with regards to medical education, medical students trained in overly simplistic approaches to diversity may devalue a patient's multiple identities and miss opportunities to improve rapport with their patients [27]. Although cultural competency is encouraged and medical student training is improving, cultural sensitivity is still lacking with regards to LGBTQ patients which may require additional training, such as differences between behaviour and identity, among other aspects of LGBTQ care [42-43]. For example, one study found that LGBTQ health is briefly taught in medical schools (median of 5 hours) and with no standardization in content covered [42]. Another review of LGBTQ healthcare training in U.S. Medical Schools found significant variability in training methods, on many occasions limited to a single lecture [43]. Similar issues of inadequate medical education on LGBTQ health has been echoed in Canada [44]. In clinical practice, physicians taking a "neutral" approach tend to reinforce heteronormative and gender-normative assumptions [18]. For instance, the gender of a patient's sexual partners is often overlooked (i.e., not asked) in electronic health records, and require physicians to make additional efforts to note important information about a patient's sexual practices and partners [45].

It may be useful for future research to explore more standardized methods of LGBTQ training as well as intersectional approaches in training medical students and physicians - e.g., incentivizing physicians with continuing medical education credits. Training focused on understanding intersectionality may improve the health care provider's ability to build trusting relationships with marginalized individuals. Yet, with diversity training alone, providers and trainees who consider themselves competent and sensitive without explicit bias may not recognize areas for improvement and miss areas to enhance patient care. It is also possible that training could lead providers to become overly sensitive and avoid terminology or detailed discussions with patients. This avoidance could be perceived by patients as provider discomfort or disengagement. Brief training alone is also unlikely to alter years of unconsciously biased thoughts and beliefs [46-49]. It may be useful to have visual signs of acceptance and openness in clinic spaces or on name badges, guidelines and staff training on how to approach sexual and gender minority patients and which topics to address sensitively, as well as having a tangible list of community resources. Other suggestions include encouraging providers and trainees to watch movies, read literature, or engage in LGBTQ community events [48-49]. Ultimately, training on an individual level is only a first step; institutional, structural, and governmental policies must also evolve to guide and create a culture that combats discrimination and microaggressions.

As with all research, our study has limitations. In keeping with qualitative research methodologies, our results are not generalizable to a given population of LGBTQ patients because the experiences in this study are highly individual and only represent the views of the participants. Since several interviewees were recruited from a centre specializing in HIV services, their experiences may not reflect the experiences of other sexual and gender minorities since HIV status is often central to health care navigation among HIV positive individuals. We did not interview any transgender individuals who were HIV positive, which may have revealed a different perspective on multiple stigmatized identities.

# Conclusions

The three themes that emerged from our research - lacking trust, being vulnerable, and navigating discrimination - underscore the need for healthcare providers to take an intersectional approach when caring for LGBTQ patients. Indeed, by recognizing and understanding the multifaceted and often stigmatized identities of LGBTQ patients, health care providers will be better positioned to care for individuals in this community. We believe that incorporating intersectional training into medical student and resident curricula would greatly benefit not only LGBTQ patients and their providers, but perhaps other patients, especially those with multiple stigmatized identities. This is an important first step in improving provider empathy, understanding, and connection with LGBTQ patients. These conclusions are in line with much of the research done over the last few decades [12-17].

#### Remerciements

Les incitatifs et les frais de transcription ont été pris en charge par Incentives and transcription costs were supported by the Albany Albany Medical College. Les auteurs tiennent à remercier le Bureau du Medical College. The authors would like to thank the Office of the Vice vice-doyen des étudiants pour leur soutien à ce projet. La transcription des entrevues a été effectuée par Cabbage Tree solutions.

### Conflits d'intérêts

Zubin Master est éditeur à la Revue canadienne de bioéthique; il n'a pas participé à l'évaluation de ce texte. Les auteurs n'ont pas d'intérêts financiers concurrents ou d'autres conflits d'intérêts concernant la recherche présentée dans ce texte.

#### Responsabilités des évaluateurs externes

Les recommandations des évaluateurs externes sont prises en considération de façon sérieuse par les éditeurs et les auteurs dans la préparation des manuscrits pour publication. Toutefois, être nommé assument la responsabilité entière de l'acceptation finale et de la publication d'un article.

Édition/Editors: Aliya Affdal, Angela Marques Filipe & Vanessa Chenel Évaluation/Peer-Review: Elizabeth Victor & Fern Brunger

#### Affiliations

<sup>1</sup> Family Medicine, Harbor UCLA, Harbor City, USA

<sup>2</sup> Biomedical Ethics Research Program and Center for Regenerative Medicine, Mayo Clinic, Rochester, USA

<sup>3</sup> Population Health Sciences, Albany College of Pharmacy and Health Sciences, Albany, USA

<sup>4</sup> Humanities & Communication, Albany College of Pharmacy and Health Sciences, Albany, USA

<sup>5</sup> Department of Obstetrics & Gynecology, Alden March Bioethics Institute, Albany, USA

Correspondance / Correspondence: Saba Malik, Smalik@dhs.lacounty.gov

Publié/Published: 10 Jul 2019 Reçu/Received: 13 Oct 2018

#### Acknowledgements

Dean of Students for their support of this project. Transcription of interviews was performed by Cabbage Tree solutions.

### **Conflicts of Interest**

Zubin Master is an editor at the Canadian Journal of Bioethics; he was not involved in the evaluation of this text. The authors have no competing financial interests or other conflicts of interests regarding the research presented in this text.

### Peer-reviewer responsibilities

Reviewer evaluations are given serious consideration by the editors and authors in the preparation of manuscripts for publication. Nonetheless, being named as a reviewer does not necessarily denote comme évaluateurs n'indique pas nécessairement l'approbation de ce approval of a manuscript; the editors of Canadian Journal of Bioethics manuscrit. Les éditeurs de la <u>Revue canadienne de bioéthique</u> take full responsibility for final acceptance and publication of an article. Les éditeurs suivent les recommandations et les procédures décrites The editors follow the recommendations and procedures outlined in dans le Code of Conduct and Best Practice Guidelines for Journal the COPE Code of Conduct and Best Practice Guidelines for Journal Editors de COPE. Plus précisément, ils travaillent pour s'assurer des plus hautes normes éthiques de la publication, y compris l'identification et la gestion des conflits d'intérêts (pour les éditeurs et pour les of conflicts of interest (for editors and for authors), the fair evaluation auteurs), la juste évaluation des manuscrits et la publication de manuscrits qui répondent aux normes d'excellence de la revue.

Editors. Specifically, the editors will work to ensure the highest ethical standards of publication, including: the identification and management of manuscripts, and the publication of manuscripts that meet the journal's standards of excellence.

# References

- 1. Wahlert L, Fiester A. Repaying the road of good intentions: LGBT health care and the gueer bioethical lens. Hastings Center Report. 2014;44(suppl 4):S56-65.
- 2. Wahlert L. Mapping queer bioethics: space, place, and locality. Journal of Homosexuality. 2015;63(3):301-305.
- 3 Foglia MB, Fredriksen-Goldsen KI. Health disparities among LGBT Older Adults and the Role of Nonconscious bias. Hastings Center Report, 2014:44(suppl 4):S40-S44.
- 4. Makadon HJ, Mayer KH, Potter J, Goldhammer HU. Fenway Guide to Lesbian, Gay, Bisexual, and Transgender Health. Philadelphia, PA: American College of Physicians; 2008.
- Meyer IH. Prejudice, social stress, and mental health in lesbian, gay, and bisexual populations: conceptual issues 5. and research evidence. Psychological Bulletin. 2003;129(5):674-97.
- 6. Fredricksen-Goldsen K, Kim H, Barken S, Balsam K, Mincer S. Disparities in health-related quality of life: a comparison of lesbians and bisexual women. American Journal of Public Health. 2010;100(11):2255-2261.
- 7. Meyer IH. Prejudice and discrimination as social stressors. In: Meyer IH ed. The Health of Sexual Minorities. Northridge: Springer; 2007. p.42-67.
- 8. Elliott MN, Kanouse DE, Burkhart Q, Abel GA, Lyratzopoulos G, Beckett MK, Schuster MA, Roland M. Sexual minorities in England have poorer health and worse health care experiences: a national survey. Journal of General Internal Medicine. 2015;30(1):9-16.
- Reisner SL, White JM, Bradford JB, Mimiaga MJ. Transgender health disparities: comparing full cohort and nested 9 matched-pair study designs in a community health center. LGBT Health. 2014;1(3):177-84.
- 10. Bostwick W. Assessing bisexual stigma and mental health status: a brief report. Journal of Bisexuality. 2012;12(2):214-22.
- 11. Makadon HJ. Ending LGBT invisibility in health care: the first step in ensuring equitable care. Cleveland Clinic Journal of Medicine. 2011;78(4):220-4.
- 12. Barbara AM, Quandt SA, Anderson RT. Experiences of lesbians in the health care environment. Women & Health. 2001;34(1):45-62.
- 13. Bauer GR, Hammond R, Travers R, Kaay M, Hohenadel KM, Boyce M. "I don't think this is theoretical; this is our lives": How erasure impacts health care for transgender people. Journal of the Association of Nurses in AIDS Care, 2009;20(5):348-361.
- 14. Bucholz S. Experiences of lesbian couples during childbirth. Nursing Outlook, 2000;48(6):307-311.
- 15. Mathieson CM. Lesbian and bisexual health care: Straight talk about experiences with physicians. Canadian Family Physician. 1998;44:1634-1640.
- 16. Neville S, Hendrickson M. Perceptions of lesbian, gay and bisexual people of primary healthcare services. Journal of Advanced Nursing. 2006;55(4):407-415.
- 17. Röndahl G. Lesbians' and gay men's narratives about attitudes in nursing. Scandinavian Journal of Caring Sciences, 2009;23(1):146-152.
- 18. Baker K, Beagan B. Making assumptions, making space: an anthropological critique of cultural competency and its relevance to queer patients. Medical anthropology quarterly. 2014;28(4):578-98.
- 19. Turner CB, Pastrana A, Battle J. From the perspectives of black LGBTs in the US: medical providers' comfort with patients' sexuality. Journal of Black Sexuality and Relationships. 2014;1(1):45-64.
- 20. Arnetz JE, Winblad U, Arnetz BB, Hoglund AT. Physicians' and nurses' perceptions of patient involvement in myocardial infarction care. European Journal of Cardiovascular Nursing. 2008;7(2):113-20.
- 21. Rachmani R, Levi Z, Slavachevski I, Avin M, Ravid M. Teaching patients to monitor their risk factors retards the progression of vascular complications in high-risk patients with Type 2 diabetes mellitus--a randomized prospective study. Diabetic Medicine. 2002;19(5):385-92.
- 22. Loh A, Leonhart R, Wills CE, Simon D, Harter M. The impact of patient participation on adherence and clinical outcome in primary care of depression. Patient Education and Counseling. 2007;65(1):69-78.
- 23. Arnetz JE, Almin I, Bergström K, Franzen Y, Nilsson H. Active patient involvement in the establishment of physical therapy goals: Effects on treatment outcome and quality of care. Advances in Physiotherapy. 2004;6(2):50-69.
- 24. Collins PH. Black Feminist Thought: Knowledge, Consciousness, and the Politics of Empowerment. New York, NY Routledge; 2002.
- 25. Crenshaw K. Demarginalizing the intersection of race and sex: A black feminist critique of antidiscrimination doctrine, feminist theory and antiracist politics. University of Chicago Legal Forum. 1989;1(8):139-167.
- 26. Crenshaw K. Mapping the margins: intersectionality, identity politics, and violence against women of color. Stanford Law Review. 1991;43(6):1241-1299.
- 27. Eckstrand KL, Eliason J, St.Cloud T, Potter J. The priority of intersectionality in academic medicine. Academic Medicine. 2016;91(7):904-907.
- 28. Lindemann JN. Medicine and making sense of gueer lives. Hastings Center Report. 2014;44(suppl 4):S12-S16.

- 29. Anderson LA, Dedrick RF. <u>Development of the trust in physician scale: a measure to assess interpersonal trust in patient-physician relationships</u>. Psychological Reports. 1990;67(suppl 3):1091-1100.
- 30. Safran DG, Kosinski M, Tarlov AR, Rogers W, Taira D, Lieberman N, Ware J. <u>The primary care assessment survey:</u> tests data quality and measurement performance. Medical Care. 1998;36(5):728-39.
- 31. Dugan E, Trachtenberg F, Hall MA. <u>Development of abbreviated measures to assess patient trust in a physician, a health insurer, and the medical profession</u>. BMC Health Services Research. 2005;5:64.
- 32. Wylie SA, Corliss HL, Boulanger V, Prokop LA, Austin SB. <u>Socially assigned gender nonconformity: A brief</u> <u>measure for use in surveillance and investigation of health disparities</u>. Sex Roles. 2010;63(3-4):264-276.
- 33. The Fenway Institute and the Center for American Progress. Asking patients questions about sexual orientation and gender identity in clinical settings: A Study in Four Health Centers. 2013.
- Sankar P, Jones NL. Semi-structured interviews in bioethics research. In: Empirical Methods for Bioethics: A Primer. Oxford: Elsevier JAI; 2008. p.117-136.
- 35. Glaser BG, Strauss AL. The Discovery of Grounded Theory: Strategies for Qualitative Research. Transaction Publishers; 2009.
- 36. Charmaz K. Constructing Grounded Theory. Sage; 2014.
- Sevinc A, Buyukberber S, Camci C. <u>Medical jargon: obstacle to effective communication between physicians and patients</u>. Medical Principles and Practice. 2005;14:292-292
- 38. Feinberg L. Trans health crisis. American Journal of Public Health. 2001;6:897-900.
- 39. Whitehead J, Shaver J, Stephenson R. <u>Outness, stigma, and primary health care utilization among rural LGBT</u> populations. PLoS ONE. 2016;11(1):e0146139.
- Kamen CS, Smith-Stoner M, Heckler CE, Flannery M, Margolies L. <u>Social support, self-rated health, and lesbian,</u> <u>gay, bisexual, and transgender identity disclosure to cancer care providers</u>. Oncology Nursing Forum. 2015;42(1):44-51.
- 41. Hankivsky O, Reid C, Cormier R, Varcoe C, Clark N, Benoit C, Brotman S. <u>Exploring the promises of</u> intersectionality for advancing women's health research. International Journal for Equity in Health. 2010;9(5).
- Obedin-Maliver J, Goldsmith ES, Stewart L, White W, Tran E, Brenman S, Wells M, Fetterman DM, Garcia G, Lunn MR. Lesbian, gay, bisexual, and transgender–related content in undergraduate medical education. JAMA. 2011;306(9):971-977.
- 43. Utamsingh PD, Kenya S, Lebron CN, Carrasquillo O. <u>Beyond sensitivity. LGBT healthcare training in U.S. medical</u> <u>schools: a review of the literature</u>. American Journal of Sexuality Education. 2017;12(2):148-169.
- 44. Glauser W. Are medical schools keeping up with the times? CMAJ. 2018;190(33):E996-7.
- 45. Nguyen GT, Yehia BR. <u>Documentation of sexual partner gender is low in electronic health records: observations, predictors, and recommendations to improve population health management in primary care</u>. Population health management. 2015;18(3):217-222.
- 46. Rondahl GS, Innala S, Carlsson M. <u>Heterosexual assumptions in verbal and non-verbal communication in nursing</u>. Journal of Advanced Nursing. 2006;56(4):373-381.
- 47. Wilton T, Kaufmann T. Lesbian mothers' experiences of maternity care in the UK. Midwifery. 2001;17(3):203-211.
- 48. Nadal KL. That's so Gay!: Microaggressions and the Lesbian, Gay, Bisexual and Transgender Community. American Psychological Association. Washington, DC; 2013.
- 49. Sue DW. Microaggressions in Everyday Life: Race, Gender, and Sexual Orientation. John Wiley & Sons; 2010.

# Supplemental Materials: Interview Guide

### **Demographics**

1. How old are you?

2. What is your race and/or ethnicity?

3. Do you currently have health insurance?

### **General Health**

4. Would you say that your health is excellent, very good, good, fair, or poor?

PROBE: What do you think prevents you from being in good health? What factors do you think contributes to your health? Tell me about how \_\_\_\_\_ has helped you

5. Do you have a primary care physician? Do you see specialists? If so, what specialty?

6. Which physician would you consider your primary provider or who is primarily responsible for your care?

7. How often do you see this physician? (e.g., annual visits; sick visits, etc...)

8. How did you choose this physician? (primary physician)

PROBE: Did you ask friends or family for recommendations? Did you look online? Did you meet with the physician once before making a decision?

- 9. Do you trust this physician? Why or why not?
- 10. How did you feel/know you could trust them?
- 11. Can you describe a time when you saw a physician whom you did not trust?
- 12. Why did you not trust them?

PROBE: Was it a specific interaction? If yes, can you tell me about an example? If you can, think about how you might have wanted the interaction or encounter to go/ be handled by the physician? Can you describe that for me?

13. Can you describe a time when you saw a physician with whom you had a good relationship?

14. What qualities do you look for when choosing a physician?

### Sexuality/Identity

Now I want to ask you some personal questions about your sexuality and sexual orientation.

15. What is your sexual orientation?

For the purposes of this study I am using the definition of Sexual orientation as by which gender(s) a person is physically attracted- gay, lesbian, bisexual, queer, pansexual, other

### 16. How would you describe your gender identity?

For the purposes of this study I am defining Gender identity as personal identification with a particular gender- male, female, genderfluid, or other- that may or may not correspond to the person's assigned sex at birth

17. (for transgender/gender variant respondents) What sex were you assigned to at birth on your original birth certificate?

18. Do you think it is important for your primary physician to know about your sexual orientation (and/or gender identity)? Why or why not?

PROBE: Can you give me an example when a physician might need to have this information and/or when they might not?

19. Is your physician aware of your sexual orientation (and/or gender identity)?

If yes, can you describe having a conversation about your sexual orientation (or gender identity) with your physician? When did this conversation take place?

How do you decide to tell a provider about your orientation?

If no, why have you not shared this information with this physician? Have you shared this information with any provider?

20. Do you feel comfortable discussing your sexuality (and/or gender identity) with your physician? Why or why not?

21. Is there anything else about sexuality and physician care that you would like me to know?

Do you have any questions for me?

Do you know of others who might be willing to meet with me to share their experiences with me for this study?